

EULAC PerMed

3rd Virtual Summer School

24th-26th November 2020

**“Implementation Research in Personalized
Medicine: Ethical, Legal and Social Aspects
perspective “**



EULAC-PerMed has been funded by the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement (GA) No 825173

DAY 3

November 26th, 14:00-18:00 CET

14.00 – 14.10

**PRESENTATION OF ICPERMED BEST PRACTICE
RECOGNITION 2021**

Dr. Maria Jose Ruiz Alvarez, D.G.R.I.C. Ministero della Salute, Italy
(ICPerMed secretariat)

Session 3

14.10 – 14.50

**ETHICAL, LEGAL & SOCIETAL PERSPECTIVE ON
HEALTH TECHNOLOGY ASSESSMENT FOR PM AND
INNOVATIVE MEDICINES AND DIAGNOSTIC TESTS**

Dr. Ramiro E. Gilardino, Managing Director & Head of Policy HE-
Experts Consulting LLC, Miami, FL. Researcher – DLP, London
School of Hygiene and Tropical Medicine, University of London



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**GLOBAL LANDSCAPE ON
PERSONALIZED MEDICINE
POLICY: KEY ELEMENTS AND
CHALLENGES**

CAMILO GARCÍA DUQUE
garciaduquec@gmail.com

14.50 – 15.30 PRACTICAL CASE. DISCUSSION VIRTUAL ROOMS

<https://youtu.be/1UkCfDnn6c>

➤ **Ethical and Legal challenges of CRISPR–Cas9:**

- genetic engineering
- clinical applications
- gene therapy

Every group will have 5 min. to present their conclusions.

➤ **R 1 : Scientifics and clinics**

➤ **R 2 : patient and family associations,**

➤ **R3 : governmental agencies, and interdisciplinary policy institutes.**



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15.30 – 16.10

E-HEALTH ON PM & STATE-OF-THE-ART ANALYSIS OF NATIONAL M-HEALTH REGULATIONS

Dr. Javier Silva, Unidad de Telesalud, School of Medicine,
Universidad Nacional Mayor de San Marcos, Lima, Peru

16.10 – 16.50

GENERAL ETHICAL ASPECTS THAT REGULATE CLINICAL RESEARCH ON PM –PARTICULARITIES IN LATIN AMERICAN

Dr. Helano Freitas, Department of Clinical Oncology, AC Camargo
Cancer Center, Sao Paulo, Brazil



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Last Remarks

Dr. Maria Jose Ruiz Alvarez

Closure of the Summer School

Dr. Rafael de Andrés. Chair of ECRIN's Assembly of Members. (Instituto de Salud Carlos III, ISCIII – Spain).

16.50 – 18.00

Ex- Member of the EULAC PerMed Coordinator

Final test and Quality Survey Online



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KEY ASPECTS & LAST REMARKS

- Interoperability of good practice Sharing Data is needed.
- ELSI and FAIR sample / data / results governance process under European and International Regulations based on
 - Participation, Reciprocity, transparency, traceability, impartiality
- GDPR, a fundamental tool to offer citizens greater protection and empowerment on personal data; and improve the circulation of such data within the EU
- Clear initial position of consent and re-consent of the minor , minority and vulnerable populations, and “News unexpected “
- It is necessary to consider the need to regulate the mechanisms that will guarantee an adequate audit of the A.I.: Evaluations periodic on representativeness of the sets data [as well as] examine the accuracy and importance of predictions”



Overall Impact: Enabling Personalised Medicine for the Citizen (data owners)

- Support uptake of multidisciplinary research and innovation results into general health practice
- Increase multidisciplinary Research & Innovation
- Promote translation of basic PM research results into clinical practice
- Promote translation of PM innovation results into the market and ensure patient benefit
- Track and communicate on successful implementation of PM in society

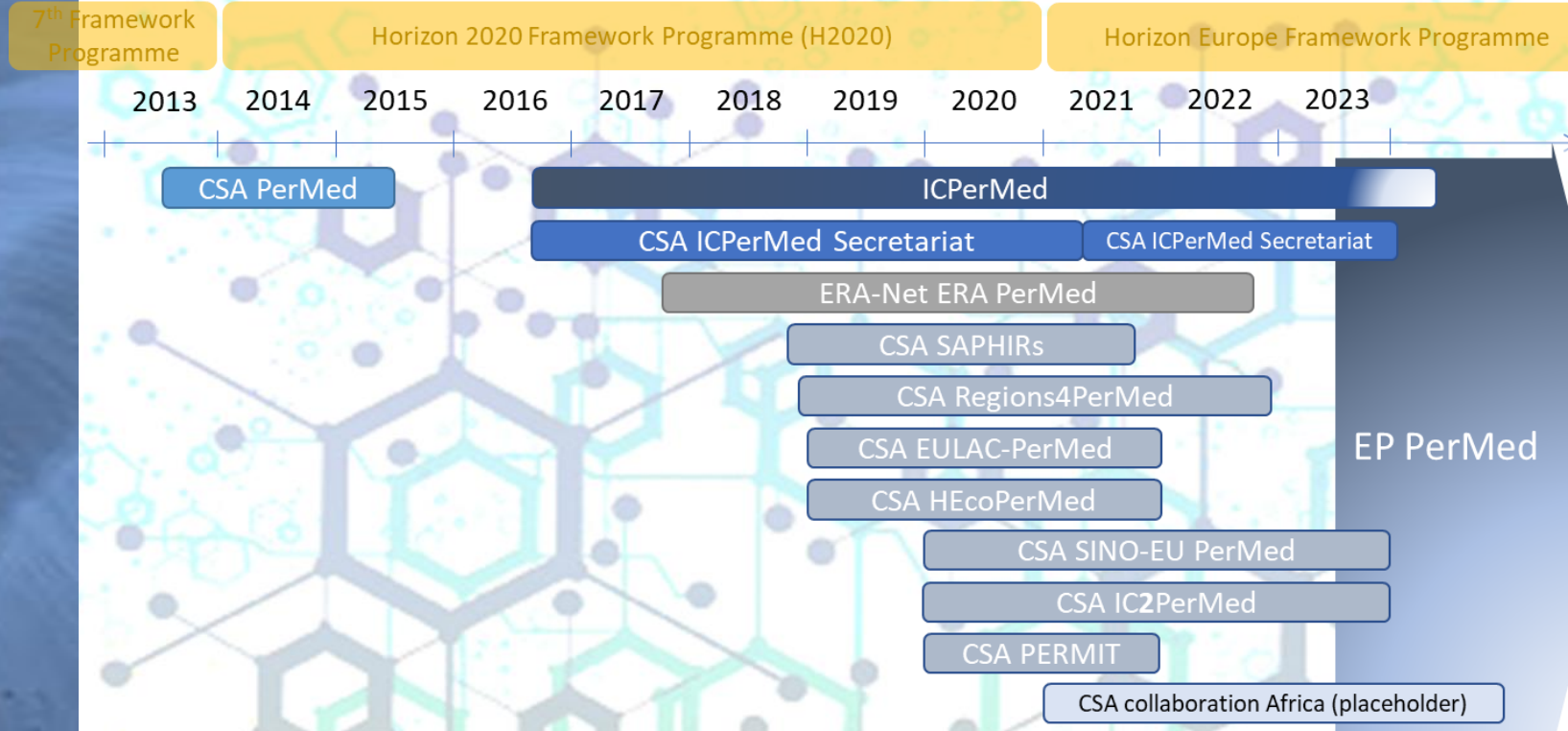


PM Implementation



- Development and implementation of funding strategies
- Development of Strategic Papers, Guidelines & Policy Papers
- Support Educational and ELSI aspects of PM
- Create Synergies: Collaboration, dissemination and networking activities
- Improve knowledge base: Research, Analyses and Mapping

KEY ASPECTS & LAST REMARKS

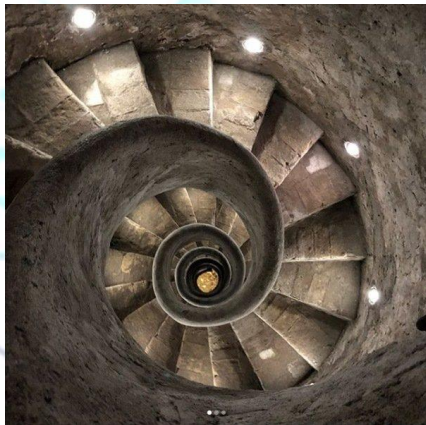


***Connecting countries health care reality with policy level,
bringing together health and innovation policy.
Aligning international and national incentives and priorities***

Support implementation of PM research



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Now , Final test time!!!!

<https://ec.europa.eu/eusurvey/runner/EULACPERMEDTEST2020>

We would greatly appreciate it if you could take a few minutes of your time and give us your feedback on the Summer School through this short survey

<https://forms.gle/C7xudnSkT7jkQyn7A>



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Thanks for your attention !!!!!!!!!!!!!

*GRACIAS POR SU
PARTICIPACION!*

See you in our Next PM Summer School !!!!

LES ESPERAMOS EN LA PROXIMA
ESCUELA DE MEDICINA PERSONALIZADA

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